

GEORGIA HEALTH POLICY CENTER



Executive Summary

The Money Follows the Person (MFP) program is a Medicaid demonstration program that was awarded to the Georgia Department of Community Health (DCH) in 2008. This executive summary, combined with the Chartbook and Data Tables, is a summary of the evaluation provided by the Georgia Health Policy Center (GHPC) for cumulative data collected between January 2009 and June 2015. Included is an analysis of Quality of Life (QoL) surveys conducted pre-transition (baseline), approximately 11 months post-transition (year one), and approximately 24 months post-transition (year two). The data examined in this report include a description of respondent characteristics, an analysis of cumulative matched surveys, Georgia-specific, supplemental questions that were phased in between June 2012 and November 2012, and open-ended, qualitative comments. In addition, the demonstration funds utilized for pre- and post-transition services were analyzed.

The MFP program has five target populations: persons with developmental disabilities, persons with physical disabilities (and under age 65), persons with a Traumatic Brain Injury (TBI), older adults, and youth with a mental health diagnosis.¹ The largest percentage of survey respondents were persons with developmental disabilities (year one: 51 percent; year two: 58 percent), followed by persons with physical disabilities or a TBI (year-one: 35 percent; year-two: 30 percent), and older adults (year-one: 15 percent; year-two: 12 percent). A slight majority of the respondents were male (year one: 55 percent; year two: 54 percent), on average respondents were 54 years old, and had an average length of stay in a facility of eight years prior to transition, though there is striking variation among the target populations. The average length of stay prior to transitioning from a facility was approximately one year for older adults, about two years for people with physical disabilities, and 12 years for people with developmental disabilities.

Survey respondents were significantly more likely to report liking where they lived, having a choice in selecting their residence, feeling safe, and sleeping without disturbances at follow-up compared to the baseline. Fewer respondents lived in a group home or nursing facility post-transition (year one: 49 percent; year two: 57 percent). More detailed information regarding housing type post-transition reveals that approximately 60 percent of the respondents lived in either an apartment or a house at year one and the shift to a larger percentage of participants living in a group or personal care homes at year two was primarily driven by a larger share of the year-two respondents being individuals with a developmental disability. The majority of respondents indicated that they live where they want to (year one: 81 percent; year two: 84 percent). In addition, 41 percent of respondents at year one and 39 percent of respondents at year two stated that they currently live with family or friends.

¹Most youth with a mental health diagnosis do not complete the QoL survey due to being under the age of 18, thus the results for the target population are not indicated separately.

Post-transition respondents indicated significantly higher levels of choice and control in their lives, including choosing when and what they ate, when they went to bed, watched television, and talked on the phone with privacy. Approximately the same percentage of respondents reported receiving help with selected activities of daily living before and after transition. A significant decline in the number of respondents indicating that they received help from someone who was paid was observed from baseline to year two. However, of those who do receive help from someone who is paid, there was a significant (34 percent) average increase observed at follow-up of those who stated that they had a choice in the people paid to help them.

Sixty-two percent of older adults and persons with physical disabilities reported that they receive informal support provided by family or friends, which averaged eight hours of help the day before. When asked if the participant needed more help with things around the house than they were currently receiving, fewer respondents stated that they needed more help at year two (14 percent) than at the year one (23 percent). Post-transition, significantly more respondents reported that the individuals who helped them treated them the way they wanted and listened to what was asked of them.

Participants' ability to do fun activities in the community and to see friends and family decreased between the baseline and year one. However, improvement was measured in these two questions at year two. Important differences among the target populations were identified with respect to participants' ability to go out independently. Nearly all of the respondents with a developmental disability needed help to go out in the community at follow-up, while significantly more older adults and people with physical disabilities reported going out independently at year two when compared to the baseline. Of those who needed help, 34 percent of respondents at year one reported needing more help than they were receiving, though at year two, the percentage dropped to 19 percent. Significantly more participants were able to get to the places they needed to go post-transition, and of those who reported not being able to get to desired destinations, the majority reported that transportation was the barrier.

Very few MFP participants reported working for pay (year one: three percent; year two: four percent) or doing volunteer work (year one: 10 percent; year two: 11 percent). Of those who were not working or volunteering, more than 40 percent of the people with physical disabilities were interested in doing so at year two. The most common barriers to working or volunteering reported by respondents included their health condition, transportation, and not being sure where to start.

A significant increase in participants' happiness with the help they received was measured at year one and year two. At baseline, 79 percent of respondents reported that they were happy with the help they received with tasks around the house or with getting around

the community as compared with 87 percent and 95 percent at year one and year two, respectively. When asked if respondents were happy with the way they live their life, a significant increase was measured at follow-up (year one: 9 percent; year two: 16 percent). At year one participants reported similar levels of sadness, irritability, and pain when compared to the baseline, but improvements were measured at year two. Cumulative open-ended, qualitative comments from 111 different participants documented during follow-up interviews were analyzed. The comments were coded into four key themes: positive transition and overall experience with MFP, challenges with the MFP program, post-transition challenges, and better quality of life post-transition. Participants indicated their happiness working with MFP staff and that their transition to a community-based setting was made possible by MFP. For example, one participant said, "This program changed my life. I want to shout it from the rooftops. It gave me my life back and I want everyone that is in my situation to experience this program."

During the follow-up interview some participants also explained that they experienced problems with the MFP program. A participant and her aide provided their experience: "I think [the MFP contractor] is lying to us. They give us the runaround. One day they say they don't know how much is left in the MFP account. The next time, they say they aren't allowed to tell us. They said they ordered the list of items we requested, but later we found out they never placed the order – they said they couldn't pay for the things on the list – and it was pretty small stuff – until they were reimbursed by Medicaid for the washer and dryer. By the time the 60 day reimbursement period was over, her time in the MFP program had ended."

Post-transition participants reported both negative and positive changes. Challenges centered on staffing, inadequate housing, and a lack of access to social activities, medical care, and transportation. For example, one participant stated, "Aides were too expensive, they provided low-quality services and there were always changing." Positive comments reflected on participants' feeling happier, healthier, more independent, having better living conditions, a sense of community, and relief to be out of a nursing home. As an illustration of this theme, a participant's sister stated, "He is 4000% better than he was in the institution. He is back to his old self, like he was 15 years ago before the institution, walking and talking. We were a little nervous about putting him back into the community, but this is the best decision we've ever made."

Before and after transition from an institution, participants have access to MFP grant funds to help pay for things not typically covered by Medicaid. From 2009 to 2014, approximately \$6.9 million MFP supplemental grant funds have been disbursed for care to support participant transitions. An observed decrease in spending on demonstration services has occurred over the last two years. The cumulative spending in 2013 and 2014 was \$429,000 less, on average, for each year than in 2012. The service categories that accounted for the largest expenditures continue to be Environmental Modifications, Equipment and Supplies, and Household Furnishings. The service accessed most frequently was the Home Care Ombudsman.